

ETHICAL DIMENSIONS OF CURRENT ISSUES REGARDING SAFE BLOOD DONATION

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DECLARATION

I, Khin San Tint declare that this research report is my own work. It is being submitted in partial fulfilment for the degree of MScMed (Bioethics and Health Law) in the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other University.

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Signature

27 day of July, 2007

DEDICATION

To my mother, Daw Sein for her ever lasting love and care.

ABSTRACT

In the HIV/AIDS literature, a perspective that has not received a great amount of attention concerning blood donation per se and the duties and obligations of Blood Transfusion Services (BTS)ⁱ when held to the question of fairness raised by socially marginalised persons (or groups) who altruistically wish to donate blood in the face of the HIV/AIDS pandemic is addressed in this research report. The represented marginalised group I use is Men who have Sex with Men (MSM)ⁱⁱ

Acquired Immunodeficiency Syndrome, commonly called AIDS first came to the attention of the public in the 1980s. From an unknown unnamed emerging infectious diseaseⁱⁱⁱ, it has grown into a pandemic familiar to all. Primarily transmitted either sexually or via contaminated needles, the HIV infected individual is initially an asymptomatic carrier. Once an individual is infected with the virus, he or she can pass it on to others by way of body fluids, e.g. blood and semen. HIV, whether treated or not, will eventually develop into AIDS for which there is currently no known cure. AIDS is uniformly mortal.

ⁱ In this research report, I will refer to the industry as “Blood Transfusion Services” although in some countries it is referred to as “Blood Bank Services”

ⁱⁱ Men who have Sex with Men (MSM) according to the London-based PANOS Institute include men who have sex with both men and women, men who have sex with only other men, men who have sex with boys and men, male sex workers and their clients, male transvestites and transsexuals, male street children and men in prison (McKenna 1999:1)

ⁱⁱⁱ As defined by Lashley, F, (2006) Emerging Infectious Diseases are ‘diseases of infectious origin whose incidence in humans has increased within the past two decades or threatens to increase in the near future’

The media abounds with literature concerning HIV/AIDS looking at it from various perspectives.^{iv} Moreover, and correctly, in South Africa we are knowledgeable that what once was considered as a threat only to homosexuals^v or IV drug users – individuals marginalised by their non-conformance to society's norms – is now epidemiologically a disease spread in our society primarily by non-drug using heterosexuals.

The tension between promoting the public good in the face of an pandemic while simultaneously protecting against unjust discrimination against individuals or groups represents an ethical dilemma faced by all public health organisations including BTS. Principally contextualised in

^{iv} e.g. clinical research in, guidelines pertaining to, ethical issues about, legal precedents concerning, duties of medial personnel towards, epidemiological analysis, psychological monitoring ...and so on.

^v At the end of the 19th century, homosexuality was profiled as a mental illness by the German psychiatrist Richard von Krafft-Ebing in his reference book *Psychopathis Sexualis*.^v In the absence of scientific evidence to prove otherwise, this view became widely accepted. Eventually, many different societies perceived homosexuals including MSM as unstable and this reinforced discriminatory practices against them.^v Even today, the harmful consequences of homophobia impact on MSM in many different ways. Meyers describes three negative conditions or practices common to the experience of MSM. They are: the internalisation of homophobia to the extent that they accept rejection from society; the experience of social stigmatisation; and overt discrimination and violence.^v

From some religious aspects, homosexuality is considered a “sin against nature” and is often seen as a link to AIDS, which is again seen as God’s punishment for a “life against nature”.^v The Koran suggests punishment for those involved in homosexual acts on the basis of harm to society, and Sharia law admits no tolerance towards homosexuality.^v. Predominantly Catholic Latin American countries enforce socio-cultural and legal restrictions to prohibit homosexuality. (Mckenna 1999:11) From Buddhist perspective, homosexuals are not permitted to become a monk and to practice through monk-hood the ultimate goal of attaining the highest level of enlightenment (Nirvana) (Ven Chanmyay Sayadaw Janakabhivamsa 1997:9). However, they are as equal as are others when following the paths taken that may lead them to attain Nirvana (Personal communication with Ven Ashin Manijoti, Theravada Buddhist Dhammodaya Monastery, Pietermaritzburg).

the milieu of South Africa but practiced globally, the responsibility of BTS's may broadly be grouped into two areas: 1) the provision of blood & its products to a given population based upon their estimated need; and 2) the assurance of blood and blood-product safety. While these may be considered only technical issues, they are not so clear-cut. Rather, they include conflicts of values and social-political agendas.

Historically, BTSs have used discriminatory practices to exclude certain groups from blood donation. Independent of country or nation and in spite of advancements in blood screening science, the existent social-political order has influence on the policies and practices of BTSs such as the separation of groups into "high-risk" and "low risk" blood donor categories. On the surface, such separations may appear to be straightforward scientific and prudential public health policy.

However, when one considers the most common manner of HIV transmission - as occurring during intimate sexual acts which take place within society's emphasis on private and individual rights but when such acts are considered by society to be 'deviant' - one might ask how the terms high- and low- risk are influenced by societal perceptions of the group in question. In other words, I suggest that societal (including political, religious, and economic) perceptions of a marginalised group's private sexual acts influence public health policy; private acts have social

consequences. Weighing the pros and cons of ethical arguments, this research report concludes that because of advanced blood transfusion science, it is morally justifiable to accept blood from *all* altruistic competent adult individuals volunteering to donate. Moreover, in this regard, it is the duty of BTS to safeguard the national blood supply by means other than excluding marginalised groups. To do otherwise is ethically unwarranted and constitutes unfair discrimination. In addition, through identifying that the act of blood donation is based on altruism or the “gift relationship,” the exclusion of marginalised groups from altruistic blood donation, serves only to further excludes them from an act, which is in essence humanity-binding. That being said, to achieve this end, all altruistic competent adults who wish to donate blood are obliged to understand the purpose, nature, and duties BTS’s have and adopt a renewed sense of social responsibility broadening our vision of the public good..

Methodology

Through using literature reviews supported by scientific, ethical, and legal evidence, and by demonstrating the tools of moral reasoning, this research report focuses on two of the major debates concerning blood safety.

The first debate concerns *how to control the spread of the HIV virus while protecting individual freedom and preventing unjust discrimination against*

particular social groups (Walters, 1990; Sullivan & Field 1989). In this regard, I will focus on Blood Transfusion Services and their duty to ensure blood transfusions are safe from emerging infectious diseases such as HIV. This I hold to the problem of a particular social group (Men who have Sex with Men) and in the context of blood donation, demonstrate that they are unjustly discriminated against and their individual freedom to donate blood is denied.

A second and linked debate concerns reasons behind the act of blood donation. Based largely on Titmuss's (1970) notion that intrinsic in blood donation is 'the gift relationship' his thoughts ground many international policies concerning BTS. I will support the altruistic notion that *Blood is a living tissue and is a bond that links all men and women so closely that differences of colour, religious belief, and cultural heritage are insignificant beside it* (Titmuss 1970).

Linking these two issues, I intend to show that arguments for the discrimination of socially marginalised groups from altruistic blood donation can be rendered tenuous at best. Moreover, I will set out to offer some good reasons how we might achieve both a safe blood supply and the protection of human liberties. This I will suggest is possible through a deeper understanding and acceptance of our social responsibility towards all our fellow humans.

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TABLE OF CONTENT

DECLARATION	ii
DEDICATION	iii
ABSTRACT	iv
ACKNOWLEDGEMENTS	x
PREFACE	xii
INTRODUCTION	1
CHAPTER ONE Blood Transfusion Services, History, Trends, Technology, and Challenges	4
1.1. A Short History of the South African Blood Transfusion Services	4
CHAPTER TWO The Changing Context of Blood Transfusion Services in Response to the HIV/AIDS Pandemic	9
2.1. Challenges to Blood Transfusion Services	10
2.2. Safeguarding Blood Supplies	11
2.3. Ensuring a Safe Blood Supply: Blood Transfusion Science	12
2.4. The Complex Window Period	13

2.5. Nucleic Acid Testing (NAT or ID NAT)	14
2.6. Emerging Infectious Diseases and The Precautionary Principle	16
2.7. Global Issues Concerning Blood Safety and Supply	20
CHAPTER THREE Some Ethical Dimensions of Blood Donation	23
3.1. Racial Profiling	23
3.2. The Donor Status Risk Model	28
3.3. MSM: Risk Status, Blood Donation, and The Donor Questionnaire	29
CHAPTER FOUR The Ethical Foundation of Voluntary Blood Donation	37
CONCLUDING REMARKS	45
References	47
Addendum (1) Donor Form of the SANBS	56
Addendum (2) The donation process	57

Preface: The HIV/AIDS Epidemic in South Africa

According to the 2006 UNAIDS report, sub-Saharan Africa has just over 10% of the world's population yet it is home to more than 60% of all people world-wide living with HIV, a total of 38.6 million (UNAIDS 2006). Within the Southern Africa Developing Countries (SADC), South Africa is one of the six countries with high HIV/AIDS prevalence rates ranging from 15 to 38 percent amongst the adult population. South Africa also has the most resources to prevent and treat people living with HIV/AIDS and now is home to the highest number of people living with HIV/AIDS in the world (Zungu-Dirwayi *et al* 2004).

In 2003, the actual number of South African people living with HIV was reported at 5.3 million of which, 5.1 million were in the age group of 15 to 49 years (UNAIDS 2006). By 2010, life expectancy in South Africa is projected to fall from 68 to 48 years because of the pandemic. The open-endedness of the current pandemic is responsible for the increase in the number of deaths attributable to AIDS (Caldwell 1997; Orubuloye *et al* 1997). In South Africa, the first cases of AIDS were identified in 1981 and were the result of infection acquired during the previous decade. Thus, the AIDS pandemic is already a quarter of a century old and the level of infection in South Africa as well as in the rest of the world, especially in developing countries, is still growing.

There are numerous social factors which appear to contribute to the pandemic. In South Africa, the HIV virus is primarily transmitted via heterosexual sexual intercourse (SAMA 2006). However, because HIV transmission involves a 'private act', early debates surrounding sex and sexuality at first were tentative and hesitant. Later, recognising the necessity to move away from the taboo of speaking openly about sex and sexuality, numerous strategies and programmes from abstinence to 'safe sex' became available, designed to inform the public of risks. In spite of risk-reduction strategies, the pandemic remains unabated. How can this be explained?

According to Caldwell *et al* (1997), the continuance of the sub-Saharan HIV/AIDS African pandemic is explained by an unusual combination of circumstances regarding sexual relationships and practices which, when engaged in, result in rapid HIV dissemination. These include e.g. the traditional practice of polygamy that, in one perspective, includes the belief that only one woman cannot sexually satisfy a man over a lifetime (Orubuloye 1997: 1199). As a result, this practice appears to sanction a considerable level of extramarital sexual relations often with parallel partners which when all combined and further extended, have the potential to facilitate the rapid spread of HIV infection.

Moreover, premarital sexual relations, it is argued, arise from the continuation of the traditional identification of a female's social value with fertility rather than virginity, thus placing young African females at high risk of acquiring HIV (WHO 1995; Varga 1997: 63). In addition, political and economic instabilities across Africa result in a substantial level of male migration and thus result in the dysfunction of traditional family and clan structures (ibid). From a health care provisional perspective, the general and long standing poor healthcare services in many South African Provinces result in numerous sexually transmitted infections (STI) being left untreated. Because they act as co-factors or catalysts to HIV acquisition, this further compounds the problem (Zungu-dirwayi *et al* 2004). Additionally, studies point out that male circumcision plays a major role in reduction of the transmission of HIV infection (ibid). In the main AIDS belt populated by almost 200 million people in contiguous ethnic groups, males traditionally remain uncircumcised although it should be mentioned that in the South African particular, circumcision is widely practiced. Although the use of condoms is widely publicised as a vital part of the 'safe sex' programmes, a study by Varga (1997) shows that unprotected sex is often seen as a sign of trust and love and it is unusual to use a condom within marriage.

Another problem is that of knowing one's own HIV status. In 2002, A South African survey by the Health Systems Trust (HST) found that many

HIV-positive people did not know their status and that individuals do not make the first move to seek HIV testing rather, the idea of testing is initiated by health care clinic workers when HIV is suspected (HST 2002). Now there is a current campaign to know one's own HIV status. This seems to be based on the premise that if one is aware of one's own HIV status, then appropriate measures e.g. provision of ART, good nutrition, acceptance of responsibility to practice safe sex, etc. will (arguably) follow. However, in spite of public campaigns recommending self-initiation of HIV testing, it has been suggested that not knowing one's HIV status (not accepting the implied responsibility), somehow gives license to unprotected sex.

A worrisome finding in this regard was reported in the Teen Pregnancy Survey conducted by the Planned Parenthood Association of South Africa (PPASA) in 2003, namely that having multiple sexual partners is a social norm amongst teenagers, and that protective measures against HIV transmission (viz. condoms) were not the norm. Additionally, it has been reported that teen-agers who acquired HIV and who were aware of it, purposely infected others based on a perversion of Ubuntu^{vi} 'death to one, death to all' (Leclerc-Madlala 1997). These are only some of the social issues raised by the pandemic, which concurrently all have ethical aspects.

^{vi} Briefly, this concept involves the well-known phrase "I am because you are I am" and places the individual within the community without which the individual would be nothing. This was rephrased during the early 1990's by labor movements, as "Injury to one is an injury to all".

AIDS in South Africa has reached endemic levels and the province of KwaZulu Natal has been disproportionately affected (Fang *et al* 2003). According to the World Health Organization (WHO), South Africa is one of the countries in a group collectively known as the “Main AIDS Belt” (WHO 1995). This explicitly identifies that HIV and AIDS have emerged as the most challenging health problem we face in modern times. However, statistics (e.g. numbers, decimals, and percentages) show no reasons or faces. Yet, staggering numbers alone should lead us to ask hard questions, seek answers, and formulate just and fair policies for all persons ‘infected and affected by HIV/AIDS’. The field of Blood Transfusion Services is not excluded from scrutiny and in this research report, I will explore some of the ethical problems they encounter in their quest to provide both the quantity and quality of blood and blood products to others in the face of the HIV/AIDS pandemic.

Ethical Dimensions of Current Issues Regarding Safe Blood Donation

Introduction

In blood bank science, the emergence of previously unknown viral diseases has resulted in public perplexity and questions concerning issues of blood safety, e.g. how sure am I to receive a blood transfusion that it will be free from HIV? My sexual life should be a private affair, so what is the purpose of divulging my personal sexual details on this questionnaire every time I donate blood? What mechanisms do Blood Transfusion Services (BTSs) have to ensure that no blood is used which is caught in the window period? ^{vii}

The need for safe blood and a sufficient supply of it is a rightful aspiration from the public that puts special obligations on the providers of blood and blood products. In this research report, I will show how the South African BTS has changed in response to the HIV/AIDS pandemic focusing on the potential contamination of blood with the human immuno-deficiency virus (HIV) and its transmission by blood transfusion. While policies and practices exist to ensure safe blood supplies I will point out that in history of blood donation in South Africa, racial profiling and the marginalisation of certain groups taints their history and process of blood collection.

^{vii} The 'window period' briefly refers to the period during which the carrier is asymptomatic (of a given disease) but potentially infectious.

Moreover I will show how cultural perceptions concerning blood impact negatively on the South African Blood supplies.

I will identify the challenges to South African BTS such as claims of racial profiling and the response by the South African National Blood Service (SANBS) to this claim. I will discuss the procedure for blood donation in South Africa which involves a 'double-screening'; a questionnaire and laboratory tests of the donated blood. The former includes enquiries about a potential donor's travel, health, and sexual life. I will point out that if respondents are honest in their answers, they may be deferred from blood donation and overall, question its (questionnaire's) current need using some of the claims made by men who have sex with men (MSM). These claims I will hold to the duty of BTS to ensure safe blood supplies.

I then turn to the moral notion of blood donation as a gift. It is internationally recognised that the safest source of blood is from voluntary donations. This is because blood, it is argued – if freely given as a gift – is only to help those in need. Voluntary donation of blood is viewed as the expression of the virtue of altruism. It is argued that if a change in the system which relies on donors giving blood voluntarily were to be replaced by paid donors, then both the quality and the quantity of blood supplies would be diminished. This, so the argument goes, is because the altruistic nature of blood donation is devalued. Moreover, if blood supplies are

reliant only on paid donations, there may be incentives to conceal any part of the health questionnaire which would lead not only to rejection of the potential donor's blood, but the refusal of payment. In South Africa, MSM have made the claim that they have a right to donate blood based on altruism. It begs the question whether altruism is not only a virtue but a right. I will argue that altruism – in this case the claim that MSM should be free to donate blood voluntarily – is like liberty: it is limited where harm or potential harm is inflicted on others.

Overall, my research report points to the complex nature of the pandemic from the perspective of BTSs. In an ethical perspective, I will reflect that the control or containment of HIV infection in blood donation relies on not only important considerations such as advances in technology, the nature of rights, or revisiting some traditional practices and current beliefs, but importantly as I will suggest, a re-thinking of our moral responsibility to others – to the common good.

To ground my research report, I now turn to explain how the context of Blood Transfusion Services has changed in response to the HIV/AIDS pandemic.

Chapter 1

Blood Transfusion Services, History, Trends, Technology, and Challenges

1.1. Historical note of the blood transfusion services in South Africa

In South Africa, blood transfusion became a regular therapy in early 1930s for treatment of blood loss due to accidents, operations or pregnancy and for patients with a severe anaemia (Gear, 1988). This was a few years after the early techniques of blood extraction, typing and transfusing had been developed. Professor J Gear was one of the founders of the first South African blood transfusion service established in the Johannesburg hospital and it recruited a panel of donors from the medical students for specific patients. The staff members of the South African Institute for Medical Research (SAIMR) were among the first donors and they were paid £ 5 for each transfusion. Also relatives of patients often volunteered to donate when needed (Gear, 1988).

The paid donation or earning “blood money” affronted the social conscience of some medical students and the Students’ Medical Council later successfully launched a campaign against paid donation. Thus the Rand Blood Transfusion Service was established in a joint venture with the Medical Graduates Association and the Students’ Medical Council. The first Chairman was Professor Gear who was succeeded by Dr

Maurice Shapiro who later played the predominate role in the establishment of the South African Blood Transfusion Service (SABTS) of which the blood donated was mainly from white donors. He constituted SABTS as one of first blood banks in the world for blood to be stored for emergency use without having to call on donors at short notice.

During the World War II, another blood transfusion service was established by the Medical Laboratory Service of the South Africa Medical Corps (SAMC) to provide blood and plasma to wounded soldiers who served the Union Defence Forces in the field and patients who suffered from shock. (Gear and Yeo, 1947). It expanded with a considerable representation in the Middle East and in Italy and established a section in the Rietfontein Laboratories (East of Johannesburg) for production of plasma and other transfusion fluids.

In 1946 a parallel blood transfusion service known as the Mines Transfusion Service which was under the directorship of Dr E Zoutendyk from SAIMR, supplied blood to hospitals of the mining industry in Southern Africa. Blood donated to the black hospitals were supplied by Transvaal Provincial Administration (TPA) and used black donors who were not volunteers but were forced to donate by their employees (Zoutendyk, 1959; SAIMR, 1964).

Later on, more segmented blood transfusion services were established in other provinces of South Africa. The Natal Blood Transfusion Service was established in Durban for hospitals in Natal and the service was based on non-payment blood donation from whites. The director of Natal Blood Transfusion Service tried hard to recruit black donors who were not part of the institutions such as from factories, hospitals, colleges or schools and in order to do so, he commissioned the study which looked at the motivation and attitudes towards blood donation among Bantu in 1965.

This documentation on the history of South African blood transfusion intends to honour those pioneers whose mission had been contributed significantly in evolving blood transfusion service from the direct patient-to-patient technique of the 1920s and 1930s to the highly structured organization of today's blood transfusion service that is responsible for providing sufficient and safe blood. Without a doubt, it was through years of painstaking in searching for new knowledge and best utilization of resources to overcome many emerging challenges, one of which was being complementary to their best in dealing ethical dilemmas and public health concern.

1.2 A Short History of the South African Blood Transfusion Services and the study on blood donation: The Attitudes and Motivation of Urban Bantu in Durban

I will begin with an overview of South African Blood Transfusion Services (SABTS) in the 1970s and highlight a study concerning donors' motivation

and attitudes towards blood donation. I will show how prevailing political ideologies influenced discriminatory practices by the SABTS and how cultural perceptions influence blood donation.

In 1970, the South African Institute of Medical Research (SAIMR) held the primary responsibility for blood procurement. At that time, there were five blood transfusion services operating in the Republic of South Africa (Titmuss 1970, In Oakley 1997)^{viii}. The SAIMR (located in Johannesburg) provided blood supplies to the White hospitals controlled by the gold mines in the Witwatersrand. A parallel blood service was allocated to the Transvaal Provincial Administration (TPA) for providing blood to “Bantu”^{ix} hospitals. The segregated services of blood transfusion were explicitly designed so that the “Bantu races will become increasingly self-sufficient in supplying their [own] needs for blood” (SAIMR, 1964).

The gold mining industry needed blood supplies for their hospitals and, as following the global trend at the time, most blood donors were paid to donate blood. Representing the social-political order of the times, in 1967 the SAIMR reported rates of pay were “Rd1 for each pint of Bantu, Coloured, and Asian blood; and Rd 4 for each pint of White blood” (ISR,

^{viii} These were the South African Blood Transfusion Service, and the Blood Transfusion Services of Natal, Eastern, Border, and Western Provinces (Titmuss, 1971).

^{ix} The use of the term ‘Bantu’ in this context does not refer to its anthropological / linguistic origins meaning ‘persons / people’. Rather, it refers to a categorization of persons into the social-political construction of the times *viz.*: “When I talk about a Bantu I talk about a Bantu, but when I talk about ‘somebody’ I mean a white person like myself” (Niekerk 1963 In Murphy 1998).

1966: 61). However, payment (or not) was left up to the particular provincial or other transfusion service. This became a problem for the Natal Blood Transfusion Service because its donors were not paid. Blood donors in Natal felt that they were being cheated and some believed that their employers were paid by the Natal Service to recruit them (Titmuss, 1970 In Oakley 1997: 126). This was reinforced by the fact that hospital patients in Natal were charged for receiving blood transfusions. Moreover, some Black recipients were charged four times as much if they received "White blood as opposed to Bantu blood" (ISR, 1966: 55).

Research carried out later (ISR, 1966) confirmed fears and anxieties about blood donation and recorded feelings from Black respondents that the atmosphere in the White-staffed blood donor clinics was impersonal, cold, and authoritarian. Reportedly, many blood donors did not seem to understand why they were donating. It reports that, at one White-staffed outdoor clinic (tent), the donors were subdued once they were inside the tent although they talked quite a lot while they were waiting outside. Moreover, these 'donors' never asked the nurse any questions or initiated a conversation (ibid).

Overall, the study revealed Blood Transfusion Service (BTS) generally had a negative image amongst the adult Bantu^x population. They were suspicious and fearful of the service because they perceived them as governmental organisations under control of the "White man" historically, the main object of their distrust.

Such examples point not only to discriminatory practices based on racial segregation but also to the ways in which a professional's attitudes towards blood donors affect the BTS. Importantly, we see how para-statal organisations such as BTS may be influenced by the politics of a particular era.

The influence of culture is also a factor in blood donation. For example, in 1966, the Institute of Social Research (ISR) of the University of Natal published their work, *Blood Donation: The Attitudes and Motivation of Urban Bantu in Durban*.^{xi} This study examined the ideas and perceptions of an average Bantuxii concerning blood donation (ISR, 1966).

The research used several qualitative research tools for exploring the personal meanings of blood e.g. "to oneself," and "good" and "bad" blood as well as the attitudes and motivations of Black blood donors. The

^x In this study, the use of the term "Bantu" referred to a person who is an indigenous black African living in South Africa (ISR 1996:4).

^{xi} This research is referred to by Titmuss (1971: 132, Oakley *et al* 1997: 252) as one of the most "thorough and intensive studies on the motivational nature of blood donation ever undertaken."

^{xii} In this report, I will now substitute the commonly used term 'Black' for 'Bantu'.

researchers observed the blood donation bleeding sessions at various blood donor clinics. The study was done on a sample consisting of several Black blood donor groups e.g. adults, medical students, factory workers, labourers, domestic workers, students, and teachers. The main findings showed that the number of donors among Black people in Durban was small and repeated and frequent donations from the same person were rare. Donors came mainly from factories and schools and tended to be younger, better educated and had a higher income than did the average Durban adult.

An interesting finding was that some of them were given orders from their superiors to 'donate'. Although they did not like the idea, they came to donate because they were afraid of losing their jobs; in other words, they were coerced into blood donation (ISR, 1966). The research further identified that for an average Black manual worker, blood is related to health, and blood has connections with ancestors. Therefore, they believe, "Our blood is their blood and we have no right to give it away" (ibid). In addition, the research showed that it seemed widely accepted that blood could not be replaced once lost. Thus, 'donors' were reluctant to volunteer for blood donation. Here it may be worthwhile to note in siZulu the word used for "giving" or "volunteering" is not used in the context of donating blood rather, the word used in this context means "to sacrifice."

The study identified that the recruitment and retention of Black blood donors is a problem which, when untangled, demonstrates how admixtures of cultural and traditional perceptions concerning the meaning of blood can have negative bearing on blood donation and thus, BTSs.

The marginalisation of peoples by racial segregation and Apartheid policies introduced a whole set of complex factors which makes it much more difficult, if not impossible, for even the now-free Black population to comprehend what is referred to as ‘the gift relationship’ of blood donation” (Titmuss, 1970, Oakley *et al*, 1997: 67)^{xiii}.

I have identified that there was discrimination along racial lines and there appears to be a psycho-religious-social complexity concerned with blood donation. I will later identify how both these factors albeit in different forms persist. I now turn to the complexities introduced to BTS in the face of the HI virus.

^{xiii} This book is an expanded and updated edition of the original edition by the New Press, New York in 1997, edited by Oakley A and Ashton J.

Chapter 2

The Changing Context of Blood Transfusion Services in Response to the HIV/AIDS Pandemic

We need to have a sound basis for understanding modern transfusion medicine. In order to do so, a reflection on the rapid pace of change around the issue of blood supply is required. One of the changes is the population projection for the world. The eligible blood donor group consists of persons from 18 to 65 years old. Based on population projections, in Western countries, there will be an increase of those above the 65 years age group while replacement for eligible donor age group will decrease (Bayer 1989). In developing countries, the life expectancy decreases are mainly due to HIV/AIDS epidemic and thus the eligible donor age group is significantly reduced. Another difficulty in blood donation in some countries, as I mentioned in the preceding section, lies in the context of cultural beliefs.

These are a few factors which will contribute to a shortage of blood supply while simultaneously, there will be increasing demand of blood because of a variety of factors such as advanced surgical techniques, organ transplants, terrorist activities, and increased use of motor vehicles resulting in more accidents. The problem of ensuring an adequate blood supply in itself comes forth as a global challenge.

2.1 Challenges to Blood Transfusion Services

Since the 1950's, when blood transfusion became a medical breakthrough, the ability to transfuse human blood to those in need as well as to ensure the non-transmission of emerging blood borne infections remains a challenge. For example, in the initial years of the USA's HIV pandemic, it was believed that HIV/AIDS was a disease exclusive to marginalised groups such as 'MSM, bisexual men, intravenous drug users, and recent immigrants from Haiti' (Altman 1986: 132). The majority of the population, perceived as heterosexuals, who if they did not deviate from socially accepted behaviour, were considered to be safe from HIV infection.^{xiv}

This perception was radically altered in July 1982 when the Centres for Disease Control (CDC) presented its Morbidity and Mortality Weekly Report (CDC 1995). The report detailed the cases of three haemophiliacs who had reported and died of AIDS and who were believed to have become infected because of blood transfusions (Bayer 1989: 71). These findings and those which followed pointed to the major hazard for BTS and transfusion recipients: viral infections can be transmitted via blood from

^{xiv} Hepatitis viral infections have historically been a particular blood safety problem (Zuch & Eyster 1996: 928).

carrier donors to susceptible patients. In the face of this crucial finding, how might safe blood transfusion ever be assured?

2.2 Safeguarding Blood Supplies

Since the onset of the HIV/ AIDS pandemic, more than 20,000 blood transfusion recipients suffering from haemophilia, as well as other blood transfusion requiring conditions have become infected with HIV (Kondro 1997; Starr 1998; Feldman 1999). ^{xv} Current findings from the WHO indicate that between five and nine per cent of HIV/AIDS cases continue to be acquired from infected blood transfusions. In the early years of the pandemic (1982 -1986) international regulations for blood safety were founded on opinions and reports arising from the testimonies of haemophiliac patients who were recipients of infected blood, rather than on scientific and medical evidence concerning what at least was then known about the virus and its mode of transmission (Weinberg *et al* 2002: 312-319).

^{xv} It is interesting to note that in response to the findings that blood and blood products were not adequately screened for HIV, in many developed countries, such individuals have lobbied for monetary compensation and instituted civil litigation against BTS. More than 20 countries have established compensation programmes that have paid out hundreds of millions of US dollars because their BTS's negligently failed to screen blood donors in the early 1980s. During this time, in the USA, UK, Italy, Japan, France, and Switzerland, the heads of national BTS's, as well as officials of various Ministries of Health who were responsible for the safety of blood, were criminally indicted (Weinberg *et al* 2002).

Because of mounting concern about blood safety, Western countries adopted “zero-risk” blood transfusion as their stated goal.^{xvi} The premise behind this is that since potential emerging diseases and disease carriers cannot yet be reliably detected, donors must be screened each time they donate blood to ensure blood safety.^{xvii}

While there is necessarily an overlap between these classifications, blood safety may be broadly classified into two aspects: 1) the technological / scientific; and 2) policy and practice. I will now turn to the former, presenting an overview of some important issues in the technological aspects involved in ensuring a safe blood supply.

2.3 Ensuring a Safe Blood Supply: Blood Transfusion Science

The complexity of transfusion science intensifies as scientific advances are achieved. While an in-depth analysis of all the technological aspects of blood safety is beyond the scope of this paper, I will highlight some of the major advances and growing problems.

^{xvi} It is worthy here to note that whatever the obstacles and in spite of technological advantages, the achievement of “zero-risk transfusion” is unlikely ever to be achieved (Fang *et al* 2003:9-19).

^{xvii} These two processes feed into other BTS’s policies and practices such as the motivational of the act of blood donation itself, the prohibition against non-voluntary and remunerated blood donations, and the emphasis upon the retention of low-risk blood donations. I will address these issues in a later section.

Blood bank services in developed countries have achieved a significant reduction in post-transfusion infection over the last two decades. This progress is the result of extensive research on transfusion-transmitted pathogens such as viruses and bacteria, the development of strategies to measure infection rates in blood donor and recipient population, the characterisation of the dynamic of early viraemia, the implementation of progressively more restrictive donor eligibility criteria, and increasingly sensitive laboratory screening methods (Busch 2003). Despite this progress, the Inter-Organisational Task Force Group of Blood Services in the United States is aware of a number of risks which continue to threaten global blood supplies - not least of which is the challenge presented by the "window period" (AuBuchon 1997).

2.4 The Complex Window Period

The window period is the name given to the amount of time between an individual's exposure to infection and the point in time when she/he "seroconverts" from antibody-negative to antibody-positive. In other words, it is the period of time between exposure and the first appearance of a detectable viral or antibody marker (Bush *et al*: 2003). "Seroconversion" is the name given to the development of antibodies in blood serum as a result of infection.

The window period is further divided into two discrete phases. The first phase is known as the “eclipse” phase. During this period, virus replication (after exposure) cannot be detected in the blood (Starr 1998; PPA 2003). The second phase is when viraemia develops, i.e. when the virus becomes detectable, and seroconversion takes place. The estimated median time between viral exposure and seroconversion is approximately 40 days, and for roughly 5% of cases seroconversion takes place over more than six months. The problem then is that because of this, donors may be infected with HIV or other blood borne infectious diseases but their blood samples will test negative if tested by older or non-sophisticated testing methodologies. While most standard screening tests are not sensitive enough to detect the infection in the window period of infection, a new genome testing method, known as Nucleic Acid Testing (NAT or ID NAT), can now detect recent seroconversion of HIV-1 and the hepatitis C virus RNA, and can therefore significantly improve the safety of blood supplies (Kondro: 1997; Feldman & Bayer: 1999; Heyns *et al* 2006). One might think that this breakthrough represented the panacea for ensuring blood safety and in many ways, it did. A brief overview of the NAT technology follows in the next section.

2.5 Nucleic Acid Testing (NAT or ID NAT)

The NAT was introduced in the United States in 1998 to screen all voluntary blood donors for hepatitis and HIV infection. Although it is

costly, it has helped to reduce the number of transfusion-transmitted infections as it is able to detect viral ribonucleic acid (RNA) early in the window period.

The NAT detects HIV infection (HIV-1 RNA) in some studies as early as seven days after a person becomes infected with HIV, while the older standard, the p-24 antigen assay, detects infection 22 days after infection (Busch & Kleinman 2000). A recent study by Heyns *et al* 2006, (based on individual studies) finds an infected window period of 8.3 days for ID-NAT. The NAT can be performed on an individual sample or on a collection of samples from a group of people known as a “minipool.”

For HIV and Hepatitis B, at least 90% of the risk can be attributed to donations of blood during the window period, while the risk rate for Hepatitis C is 75% (Busch & Kleinman: 2000). Interestingly, laboratory methods can find no evidence of infection during the first phase of the window period. Typically, this period lasts for ten days but it can be as long as several months. Because evidence of infection in this non-viraemia or “eclipse” phase cannot be detected by even the most sensitive NAT, it has been thus far concluded that the blood of an infected person is not contagious at this time (Fang *et al*: 2003). Moreover, according to this South African study, the actual risk of the non-viraemia phase may be lower than was earlier assumed, because viral concentrations in blood

may be below the infection threshold in the first few days after exposure (ibid).

While this advanced genetic technology enables us to narrow the window period of infection, because we can detect HIV infection very early, it comes at a very high financial cost. In spite of this, NAT with its dramatic technology has led to pressure from legislators, regulatory authorities, and the public to put it in practice to enhance further transfusion safety (Busch & Kleinman: 2000). Moreover, a spin off from this has strengthened regulatory oversight of BTSs resulting in quality assurance programmes in blood collection and transfusion facilities, for example in the USA by the Food and Drug Association (FDA) (Busch & Sattern: 1997).

The advanced technology of the NAT has provided evidence for investigations into cases where a donor's blood was linked to the development of AIDS in a transfusion recipient. It has also proved that exposure to as little as one unit of infected blood may result in HIV or other viral transmissions (WHO 1995; Curran 1984: 71).

The American experience has shown that blood is now so safe that it has become virtually impossible to quantify the transfusion risk. Can we say then, in spite of financial cost, that the benefits of NAT outweigh any

costs? Unfortunately, this is not the entire story. I now turn to some rising issues in blood transfusion safety and blood supply.

2.6 Emerging Infectious Diseases and The Precautionary Principle

Klein (2000: 238), reporting on behalf of the USA's National Institute of Health (NIH), has questioned whether blood transfusion will ever again be safe enough, even with a comprehensive safety system in place, due to unknown emerging infectious threats.

We know little about most of the emerging transfusion-transmissible infections such as Creutzfeldt-Jakob Disease (CJD) and human Transmissible Spongiform Encephalopathy (TSE), and standard serological screening techniques have not managed to define window periods for transmission of these new infections (Mitka 1999). For blood recipients, the greatest risk in this is that blood supplies, in spite of all technological advancements, may be less than 90% safe. Emerging infections will continually threaten the blood supply around the world, and blood services internationally need to develop mechanisms to address these risks. One way of risk reduction is based on a weak application of what is referred to as the Precautionary Principle, an explanation of which I now turn.

Management of blood borne disease transmission risks is a weak interpretation of the “precautionary principle” which states that

complete evidence of risk does not have to exist before instituting measures to protect individuals and society from that risk (Wilson et al 2003: 90).

In the 1970s, this principle was used by environmentalists from Europe as well as in international treaties among Western countries for the purpose of protecting environmental quality (UN ED 1992). Concerning BTS practices though, the meaning is not quite as clear. Nonetheless, it was put into effect by the Canadian Blood Supply System when, between 1980 and 1996, a new infection known as CJD became a public health concern. In this case, the Commission of Inquiry for Canadian Blood Services rejected the view that complete knowledge of a public health hazard is a prerequisite for action, and deferred blood donations from individuals who had spent six months in the United Kingdom during the bovine spongiform encephalopathy outbreak which resulted in a variant of CJD in humans (Wilson et al 2003; Krever 1997).

Although the principle is widely used, the concept has been criticised for being a mechanism to introduce trade protectionism, resulting in over-regulation, denying the public the benefits of new technologies, arousing

unnecessary fear in the public about health risks, and making the scientific process irrelevant (Wilson *et al* 2003: 90).

To clarify the intent of the precautionary principle, in 1998, the Science and Environmental Health Network convened a symposium known as the 'Wingspread Conference' and defined its four components: 1) preventive actions should be taken in advance of scientific proof of causality; 2) the advocate of an activity should bear the burden of proof of safety; 3) a reasonable range of alternatives should be considered; and 4) for making decision-taking precautionary it must be open, informed, democratic, and must include all potentially affected parties (Mann 1996:6).

Mathematical models used for risk estimates of HIV and Hepatitis B take into account four possible sources of risk. According to Busch & Kleinman (2000), sources of risk in blood safety include problems when:

- the sample produces a negative result when tested during the window period;
- immunovariant strains cannot reliably be detected by current serological assays;
- some individuals are persistent antibody negative (immuno-silent) carriers; and
- False results due to the procedural testing errors.

So, the advancement in technology and the uneven application of the precautionary principle has not resolved all our blood safety-related problems. An ongoing concern is the management of donors whose blood gives a negative result when tested with standardised serological tests such as antibodies, Polymerase Chain Reaction (PCR), and p24 antigen, but which becomes reactive when tested using the NAT. Consequently, blood services are challenged and compelled to explain the complexity and significance of these test results to the donors.

Furthermore, the expanded deferral or screening of donors threatens the adequacy of blood supplies. We are aware that problems involved in ensuring ultimate safety (i.e. zero-risk blood supply) is not confined to technology alone. Public trust (e.g. eroded in the recognition of haemophilic acquisition of HIV by blood transfusion) concerning blood safety remains a critical concern. In this regard, Busch *et al* (2003) conclude that stringent donor deferral policies may be necessary to regain the trust of the public, but that it is also important to balance safety with the need to maintain an adequate and affordable blood supply. This is a global concern.

2.7 Global Issues Concerning Blood Safety and Supply

Approximately 70% of the world's nations do not have policies in place to ensure a safe blood supply (WHO 2005). Developing countries often lack

political will, financial resources, adequate numbers of health care personnel, developed health infrastructures, and have limited health budgets which compete for health priorities. In addition, increasing globalisation of trade has forced governments of developing countries to reduce their health care service and delivery budgets. Cumulatively, this has resulted in less care and attention is paid to the safety of blood supplies. WHO (2005) estimates that 13 million donations a year are not tested for HIV or HCV. An additional point is raised by some authors (Kleinman & Busch 2000; Goodman 2004) concerns the global connectedness of blood supply. They identify that global travel and migration result in the dissemination of new and emerging microorganisms, a point noted in the history of HIV dissemination (Klein 2000: 239). This coupled with new threats such as bioterrorism may endanger the integrity of blood safety (UN AIDS 2006). Busch *et al* (2003) foresee the emerging danger and recommend that it is the responsibility of the developed countries to improve the safety of blood in developing countries where resources are insufficient for screening of all donations of blood. In these ways, we can see the global connectedness of blood safety and blood supply. Whereas vast strides have been made in blood transfusion science and understanding the nature of the act of blood donation, hurdles remain towards the ideal of zero infectious disease transmission.

The recruitment and retention of regular healthy donors is one of the most important steps to ensure the safety of blood. To this end, the WHO (2005) advocates a national blood policy that embraces voluntary non-remunerated donation by a donor pool selected for its low-risk, i.e. all donors should be screened for risk factors using donor questionnaires and educated to avoid risky behaviours. For example, at the start of the HIV/AIDS epidemic in the USA, most BTSs as well as the Centers for Disease Control (CDC) believed that they had a duty towards transfusion recipients to consider a more restrictive policy for blood donation than they then had in operation.

Worldwide, the major threat to the meaning and justification of self-sufficiency in blood safety and supply is the contamination of blood supply with HIV or other transfusion-transmittable infections. In order to obtain safe blood from donors particularly amongst whom there is likely to be a high prevalence of HIV, a selection method has to be in place. The selection method has caused great controversy and in that framework, it raises some of the most critical ethical debates concerning blood donation. It is to some of these issues I now turn.

Chapter 3

Some Ethical Dimensions of Blood Donation

Several ethical issues relevant to blood donation have been highlighted by the recent crisis in the South African National Blood Service (SANBS). In this section, I will look at three of the major ethical issues concerning blood safety and supply 1) Racial profiling which was seen by many as the medical stigmatisation of population groups by excluding them from blood donor pools and 2) Sexual profiling, which is viewed by some as unfair discrimination and 3) The importance of honesty and altruism to ensuring safe blood supplies. These I will frame in the broader context of the relation between public health duties and the rights of individuals and groups.

3.1 Racial Profiling

South Africa had over six million people infected with HIV at the end of 2004 and the rate of infection in young women attending public antenatal clinics increased from 13% in 1990s to 38% in 2003 (NDoH 2004). The Black population has the highest prevalence rate of HIV (Connolly *et al* 2004). A demographic analysis of blood donors from 1999 to 2000 confirmed that the group most at risk of donating HIV-infected blood are Black, female, first-time donors aged 20 to 30 years, followed by both sexes of Black persons. Because the largest incidence of HIV-infection is

amongst the Black population and amongst them mainly women in their reproductive age, and in view of the BTS's duty to issue the safest possible blood, risk profiling appeared to be the best way to approach the problem. In 2003, the SANBS confirmed HIV-1 transfusion transmission in one to two recipients each year, and projected that if the racial profiling of blood donors was not applied then there would be approximately 90 recipients of HIV-infected blood per year (SANBS 2003).

Racial profiling as a blood safety screening method was used by the SANBS since 1999, and by 2003; it resulted in the decline of the HIV prevalence in blood donors to 0.05%.^{xviii} There is further evidence of an improvement in the safety of blood. For example, residual risk of collecting an HIV-1 infected unit of blood was 2.6 per 90 000 donations in 2001-2002 and the risk of transmission during the window period decreased by 24% from 1999 to 2001 (Fang *et al* 2003).

Suffice to say that the provision of safe blood to South Africa's citizens is a legitimate and important social goal, but the means to its end of providing safe blood became a problem in the face of politics, "race and blood" (CT 2004). In brief, the SANBS' racial profiling policy was raised as an issue in late 2004 by the Cape Times (CT) when a nurse working for the SANBS was dismissed following her refusal to continue her employment contract

^{xviii} This is in contrast with the persistent increase of HIV infection in young women as measured at antenatal clinics.

because she considered the policy of racial profiling as a mean of determining high-risk for HIV infection objectionable (CT 2005). To this, the then-medical director Robert Crookes replied that the system was the “most logical, medical, ethical, and legally defensible method available” [to ensure blood safety] (Carroll 2004). This resulted in a response by the Minister of Health that the SANBS racial profiling policy, “Smacked of racism” (DoH (SA) 2005) as well as outcry from the Human Rights Commission (CA 2004). Later, the public came to know that President Mbeki’s blood donation had been discarded as a result of the existing policy and that moreover, as a first time donor he declined to complete the donor questionnaire (KaiserNet 2005).

We know from history that from 1948 to 1994, Black South Africans suffered more than 40 years of institutionalised racism under the Apartheid government. In an earlier section, I pointed out that during that time racial discrimination in BTS was common practice. This was due to the pervasion of the Apartheid ideology into all spheres of living. One may ask in this regard if the racial profiling debate was not fuelled somewhat by the vestiges of Apartheid policy and practices.

According to the South African Constitution, discrimination based on race is unlawful unless it can be proved that such discrimination is not unfair. So the question which surrounds the issue is the use of racial profiling as a public health measure to ensure safe blood supply: Was it unfair to use

that particular marker? On the affirmative side, it has been argued that sensitivity concerning race as a risk marker limits its use for population profiling a public health risk (Ellison 2005: 67). Similarly, Bekker and Wood (2006: 558-558) argue that race is an imperfect “surrogate” and that it is a social construct that carries with it many other associated variables, such as language, culture, health beliefs and socioeconomic status. Therefore, on its own it is not a sufficient warrant for use. On the other hand, racial profiling of blood donors is one of the public health measures which have as its aim the maximisation of public welfare. In the BTS perspective then, the practice is not racist per se, as the focus is on overall blood transfusion safety; safe blood is available for *all* races.

Nonetheless, eventually the policy became so politically heated that it failed to obtain support from the National Department of Health and has subsequently been withdrawn. The major ethical question seems to surround the issue of protecting the common good while respecting individual rights (viz. against discrimination based upon race) as well as pointing to different perceptions (e.g. politics versus science) on the blood safety issue. Concerning the latter, forensic scientist David Klatzow was reported as saying, “It is a tragedy that the AIDS incidence follows the socio-economic inequalities of the past, but to deny that in the approach to safe blood is to take one tragedy and convert it to a second tragedy - with the additional element of farce thrown in” (CA 2004). At the same time,

Professor Solly Benatar, a well-known South African ethicist was reported as saying racial profiling was “effective but abhorrent “(Herman 2006). Yet, in South African society, other significant transformation processes do use racial profiling. One of these is the affirmative action of the Employment Equity Act, 55 of 1998 (EEA 1998).^{xix} So we are obliged to ask if the use of the term ‘racial profiling’ is understood and applied fairly and consistently by the public and those in political offices.

Bateman (2005: 206) writing in the South African Medical Journal captured a thoughtful understanding of the problem reporting,

“A black journalist writing in a Johannesburg newspaper said that she cared less about political correctness and more about her little daughter receiving safe blood. Racism in the past was when the blood organisation gave blood donated by white people only to white people and that donated by black people only to black people”.

^{xix} Affirmative action is the Government's commitment to the transformation of the Public Service into an institution whose employment practices are underpinned by equity. The affirmative action measure has preferential treatments and numerical goals to ensure equitable representation of designated groups, meaning, Black people, women, or people with disabilities. This new framework for human resource development and management has a time-bounded target for each group and requires monitoring and evaluation (GG 1998). Within the target time bound, affirmative action is for the common good. Some who argue against this policy make the claim that the so-called transformation policy could be viewed as discriminatory and should be replaced by a policy of “equal opportunity.”

3.2 The Donor Status Risk Model

In October 2005, the SANBS implemented their new Donor Status Risk Model and ID NAT screening which replaced the contentious racial profiling type.^{xx} This model is based on statistical analysis of blood donations designed to identify demographic indicators generally linked to HIV infection. Reportedly, significant risk indicators are donor types, 24-month donor history, geographical location of the donor clinic and donor age and gender (Heyns *et al* 2006:203). These considerations are reinforced by donor education and exclusion (SANBS 2005). This model, supplemented with extensive ID NAT testing, would appear to be a political compromise over the issue of racial profiling.^{xxi} Or is it? It is notable that a subtle indicator of racial profiling may be conceived in the 'risk indicators' i.e. the geographical location of the donor clinic which could serve also as a racial indicator.

Perhaps the lesson learned is that pressures placed on the SANBS from whatever factors (e.g. misunderstanding of terms used in a technological sense, political ideologies, explosive mediasation of issues concerning

^{xx} The procedure involves blood from first-time donors screened for transmissible disease screening with plasma quarantined and only issued after the donor's second donation is clear of any infective agent (Bekker & Wood 2006).

^{xxi} It is interesting to note that racial profiling was approved by the Department of Health and the Department of Health is represented on the SANBS Board (Holleman 2004).

blood donation, appeals to protection of political figures^{xxii}, mis- or ill-communication, or rightful concerns about the rights of individuals to be free from racial discrimination etc.) did serve the purpose of challenging the norm requiring that they review racial profiling and the result has been the creation of new ways of looking at the problem. And in that regard, the SANBS rose to the occasion.

Yet, the questions prevail, should the rights of one racial group who are at high risk of transmitting HIV via blood donation trump the rights of all racial groups in need of safe blood transfusions.

3.3 MSM: Risk Status, Blood Donation, and The Donor Questionnaire

In South Africa, the estimated risk of transmitting undetected HIV through the blood of donors in low-risk HIV categories increased from 0.62 per 100 000 in 1996, to 0.99 per 100 000 in 2000. For the same period, in high-risk HIV categories, the risk decreased from 50 per 100 000 in 1999 to 38 per 100 000 in 2000 (Heyns 1999; Fang *et al* 2003). Blood service organisations all over the world use a donor questionnaire that includes self-selection and self-exclusion.^{xxiii} Such questionnaires include one's personal history (encompassing medical, sexual, and travel history; for

^{xxii} "I don't have to remind you what happened to our President's blood ...something unheard of all over the world. That was a difficult moment for all of us" Health minister Manto Tshabalala-Msimang quoted by Evans and M & G staff 2005).

^{xxiii} See addendum 1: SA donor questionnaire.

example, last time blood donated, record of operations, illnesses, any known illnesses such as Hepatitis, HIV; last time visited the UK, if ever lived in South Africa, etc.)^{xxiv} Questionnaires may be country specific. For example, if government personnel are concerned about 'mad cow disease', then they will restrict blood donations from a person who they consider may be at risk for coming into contact with that particular virus or it's variant. The prospective donor's sexual history includes *inter alia*, casual sex, anal sex and male-to-male sex (WHA 1995, SANBS 2000). (All male-to-male sexual acts are assumed high risk.)

Through the self-selection method, potential donors who fulfil the low risk requirements are immediately eligible to donate blood and their blood is drawn. Self-exclusion refers to those who do not fulfil the requirements for blood donation, be it based on medical, sexual, or any other type of required information. They are immediately rejected on site as 'high risk' and their blood is not drawn. Thus, we see that the process for becoming a qualified donor is lengthy and detailed.^{xxv} And we see that the initial grounds of acceptance (the self-selection or self-exclusion questionnaire) rely upon the honesty of the potential donor. Thus, blood safety relies on

^{xxiv} The last two questions are specific to Canadian BTS (J. Nkosi, personal communication March 2007)

^{xxv} All such methods start with sensitive screening tests which have been, for more than three decades, considered as a cornerstone of blood safety (Klein & Anstee 2005). The collected blood then has to undergo a system of "layers of safety" which is considered as part of the duty of blood banks in order to inspire public confidence (AMA 1986; Klein 2000).

scientific technology ^{xxvi} (mechanical means of detecting blood borne diseases) and truthfulness on the part of any potential blood donor.^{xxvii}

Linked to other contemporary South African issues of blood donation, the questionnaire has been the focus of other ethical debates. This time, it is MSM who came into the limelight. The following are some of their claims:

1) Since no clinical research has been done on the HIV status of South African MSM per se then there is no scientific evidence on which to justify blood rejection based on their being at high risk for HIV. Therefore, the policy is “offensive and discriminating” (Green 2004: 2) They are unfairly discriminated against by the government when held to another group of donors who are proven to be at high risk, but now are acceptable as donors. 3) Since technology exists to appreciably close the “window period”, the questionnaire concerning one’s sexual life is irrelevant and 4) The rejection of their blood based on sexual orientation is against their Constitutional rights.

Let us try to unpack these claims. 1) Indeed, with MSM we can agree that thus far there has been no epidemiological data concerning HIV

^{xxvi} The problem of transfusion-transmitted diseases was addressed by routinely screening all donations for the presence of HIV-1 by p-24 antigens, antibodies to HIV-1 and HIV-2, antibodies to hepatitis B virus, and syphilis. (Heynes et al 2006). This practice has now been changed as I will mention later.

^{xxvii} The latter is paramount to blood transfusion safety particularly in countries in which no other protection measures for blood screening are available.

prevalence in MSM in South Africa per se, and there is data on the HIV risk of heterosexuals (Connolly *et al* 2004: 760).

To counter these claims, the MSM community would have to identify just how their sexual practices differ from the sexual practices of other MSM in e.g. USA, Europe, Singapore, and Taiwan who have empirically been shown to be at high risk. But they claim that since the advent of global safe sex campaigns aimed at MSM communities, any empirical study would be irrelevant as they never had a base line study carried out in the first place (SAPA 2006). Of course, there is research that looks at the relationship between male-to-male sexual acts and transmission of HIV infection, which concludes that there is a high HIV transmission rate amongst MSM.^{xxviii} And the SANBS uses such evidence for its risk management approach to blood safety. Concerning a study of HIV prevalence, a spokesperson for the Triangle Project, a gay and lesbian organisation in Cape Town said, “It will not be asking the [health] department to survey the gay community. It will be incumbent on the gay community and its organisations to do something about it” (ibid). These are, I suggest, weak arguments. However, in support of MSM groups, the South African Human Rights Commission has, according to reports,

^{xxviii} A cohort study conducted in the United States explored all known risky sexual behaviours as well as looked at the benefit of screening for HIV and the consequent reduction in transmission, and found that in situations where screening is not performed, HIV-infected MSM transmit the virus to 1.12 sexual partners over their lifetime, while heterosexual men and women transmit the virus to 0.42 and 0.14 partners, respectively. In a more recent article, Yi-Ming and Hsu-Sung Kuo writing in *The Lancet* (2007: 623) report HIV 1 infectious rates of 5.2 to 15.8 in MSM in Taiwan.

“requested the SANBS, the Medical Research Council (MRC) and the Council for Scientific and Industrial research to probe the applicability in South Africa of international findings that homosexuals were a high-risk group” (SAHRC 2006).^{xxix}

The third claim, concerning the narrowing of the window period, it is true that since early October 2005, the SANBS has performed the NAT on individual donor and on all units of donated blood (Heyns *et al.* 2006: 203-208). The introduction of universal NAT ID on individual testing has narrowed the window period. Consequently, it provides the opportunity to validate recently infected donors and verify the true risks of HIV-1 transmission. This does raise the query whether the questionnaire is used for discriminatory purposes. If all samples do really undergo NAT or NAT ID, then one could argue the reasonability of the two-tier safety system asking about the moral justification for the questionnaire. In addition, sexual activities such as oral and anal sex are ‘universal’ human sexual practices not confined only to MSM (MG 2006).

Their strongest argument is the second claim that since young Black women between the ages of 18 and 24 who carry the greatest risk of being HIV positive are now eligible to donate, then to discriminate against

^{xxix} Intuitively, one might argue that it would be most unusual for South African MSM to be different in their sexual practices than MSM in other countries.

them, based only on their sexual preferences (identified in the way they truthfully answer a questionnaire) is unfair discrimination. Their claim concerning inequity relies on the fact that the previous discrimination of a known high-risk donor group has now been included in blood donation practice and policy (UNAIDS 2005; Matlase 2006). But the second part of their claim, that the SANBS should also include donations from a perceived high-risk population if it is to be fair and equitable would require some scientific evidence if it were to be accepted.

At the heart of the issue is whether the policy and guidelines applied by the SANBS to MSM constitutes fair or unfair discrimination. Human rights groups and MSM in South Africa have expressed the view that the donor self-exclusion questionnaire is discriminatory because it is unfair (SAHRC 2006). This is based on what they call the “insensitive” wording of the question that asks a prospective male donor whether he has had male-to-male sex within the past five years (see SANBS Donor Questionnaire part 2 2006).

4) Another argument against the SANBS put forth by human rights groups and activist MSM organisations is the argument from ‘rights’. They argue that the guideline used by the SANBS violates the “right to donate blood.” While the Bill of Rights does not mention the ‘right to donate blood’, it is assumed that the rights to which they refer may be e.g. the right to

equality and the right to human dignity. The use of 'rights language' as exemplified above is often misguided and misapplied as it usually omits the co-responsibility of duty. However, a point they raise is the nature and intent of the questions asked in relation to one's human dignity and equality under the Constitution.

While the South African Constitution embraces equality, the equality clause does not prohibit discrimination in general, but rather unfair discrimination. Section 9 (3) of the Equality clause declares that the State may not unfairly discriminate directly or indirectly against anyone on the grounds of race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language, and birth. These grounds are known as the 'listed grounds' in s.9 of the Constitution (Currie & de Waal 2005: 261).

As such they require that the person / entity accused of unfair discrimination bear the onus of proving that the discrimination was, in fact, fair (Feldman & Bayer 1999:162-165). In the context of MSM and their claim of unfair discrimination, we will wait to see if this is brought to the Constitutional Court for decision.

Similar to the early years of the HIV/AIDS epidemic in the USA, there was considerable dialogue between the Public Health Service's Executive Task

Force on AIDS and representatives from blood banks, public health officials, and leaders of MSM regarding blood donation. This was brought to the forefront as the USA government, because of the prevalence of HIV/AIDS in the MSM community (and fear of its spread beyond),^{xxx} exercised its public health powers by forcing the closure of gay bathhouses, thus restricting the liberty of MSM. The bathhouse debate focused on the clash between the demands of sexual privacy and the protection of public health (Rabin 1986: 729-747). We can see some similarities in questions South African MSM raise and some of their issues should compel us to debate questions such as the particular issue of privacy versus liberty; to ask how much scientific evidence is necessary before one's liberty is restricted (Bayer 1989: 79-90) and so forth.

Once again, such questions lead us to the tension present in the duties of BTS to protect the public's safe blood supply while adhering to the principles of individual liberty and freedom. We are obliged to ask questions concerning if and if so on what grounds do we discriminate against those who have a sexual orientation which is outside societal norms, and if it is in fact unfair discrimination, to justify this openly in reasoned public discourse.

^{xxx} Recall at this time scientific understanding of HIV was not well understood and this, combined with societal prejudices blurred many issues.

Chapter 4

The Ethical Foundation of Voluntary Blood Donation

Under present conditions, any system to safeguard blood supplies will require sensitive screening tests – but this represents only one component of the system. The WHO advocates for each country to adopt a national blood policy that embraces voluntary non-remunerated donation by a donor pool selected for low-risk, i.e. all donors should be screened for risk factors and educated to avoid risky behaviours (WHO 1995-2000; Klein 2000; UNAIDS 2006). This approach not only shifts the nature of the act of blood donation but also requires that the public have confidence in the integrity of BTSs. To meet this end, BTS operational systems should have “layers of safety” (Klein 2000: 238-240). These include effective donor education; stringent screening, selection, and deferral procedures; post-donation product quarantine; donor notification and, when the screening test result is positive, positive result case-based training. In addition, all BTS organisations must have a technical vigilance system to address previously unknown emerging infectious disease threats. To ensure blood safety, the recruitment, and retention of regular low-risk healthy donors is one of the most important steps in blood safety management. Other considerations involve the motivational of the act of blood donation itself, the prohibition against non-voluntary and remunerated blood donations, and the emphasis upon the retention of low-risk blood donations. All these factors constitute the ethical duties of BTSs.

With the advent of HIV, the situation in this regard becomes tenuous. This is due to not only economic reasons but blood transfusion technology as well. For example, in many developing countries, the major contribution to the blood supply has come from paid donors – it has now become a custom. Moreover, many nationalised BTSs have been unable to bear the costs of implementing the WHO guidelines that require screening of all donated blood. It is argued that all governments have an obligation to weaken the market for remunerated blood transfusion and, through social policy, enforce “the voluntary blood-donor system” (Declaration of Paris 1994; GCBS 1995; Titmuss 1970). In addition to this and following the WHO guidelines, many BTSs have converted from a paid donors approach to that of voluntary donation. To be successful, voluntary donations rely on improved donor screening, community education programmes concerning the act of giving or donating, and implementation of reliable and sophisticated blood screening technologies (Declaration of Paris 1994; WHO 1995; GCBS 1995; Klein 2000: 238).

Global shifts in ways of thinking about the act of blood donation have resulted in changes. From the time when focus shifted to the altruistic nature of blood donation there have been lowered rates of HIV infection due to blood and blood - product contamination. Since the implementation

of such guidelines based on Titmuss^{xxxix} work, scientists and researchers have observed a dramatic reduction of HIV prevalence amongst blood donors (Busch *et al* 2003: 959-952; Kleinman & Busch 2000: 647). It would appear, then, that implementation of these new approaches to blood safety has merit – and this is true.

Blood donation has become well accepted as a “social responsibility” since the mid 1970s when Titmuss developed his theory that only voluntary blood donation ensures the safety of blood supply. He proposes that, in this context, “we need to ask what conditions, systems, structures, and social policies permit and encourage maximum truthfulness on the part of the donors, or discourage and destroy the voluntary and truthful gift relationship” (1997: 257). He considers that voluntary blood donation represents the purest form of human gift-relationship, and that it ensures the safety of blood.^{xxxix}

As already discussed, voluntary blood donation by unpaid donors is viewed as an expression of altruism as well as the best means to an end –

^{xxxix} Titmuss used blood donation as a model for examining how altruism and social policy might work together in a modern industrial society. He exemplified blood donation as a gift relationship: blood donation is a social service and an act of altruism (Titmuss 1970).

^{xxxix} Titmuss compares the quality of the British blood service which relied on voluntary blood donors to that of the American one which was profit orientated. He shows that a non-market system based on altruism (British blood supply) is more effective than one (American blood supply) that regards human blood as a commodity. The cost of blood was five to 15 times more in America than in Britain and about 30 percent of collected blood in America was wasted compared with two percent in Britain. More importantly, WHO (1995) reported the blood in America was about four times more likely than British blood to infect its recipients with hepatitis, which was the main threat in that time..

ensuring adequate and safe blood supply, that is. On the other hand, blood banks have the obligation to ensure the safety of blood. In order to achieve this, blood banks impose some safeguards, namely the completion of a questionnaire and mandatory testing for HIV. This implies that the donor is truthful and honest in answering the questions. The quandary is that, because of the intrusion in the donor's privacy, honesty can result in being excluded from donation. Recall, in the specific case of MSM and the refusal of the SANBS to accept their voluntary donations of blood, it is argued that this is a form of unfair discrimination. Certainly, as MSM are human beings and as such have an intrinsic worth no matter their sexual preferences, they have a right to be treated with respect and dignity. In this sense, to treat them otherwise represents unfair discrimination. It follows, that MSM are denied the right to human dignity of which, at least on a higher plane, altruistic behaviour is a part.

Following Titmuss' view, that blood donation is the epitome of the human gift relationship, otherwise called altruism; let us now unpack the concept of altruism. Altruism or unselfishness is an expression of concern for the other. It is a supererogative action or an action that is beyond the call of duty. In other words, no one is obligated to be altruistic. It is a virtue, a form of moral excellence.

Scottish philosopher David Hume's concept of altruism refers the capacity to be moved or affected by the happiness and suffering of others, rather than compassion or pity (Norman 1993: 71). According to Hume, a moral motive has the interests of others at heart; it entails action motivated by the desire to be generous, friendly, and helpful. Acting from selfishness, he argued, is not a moral motive even if it results in a morally right action (Beauchamp 1998). For Hume, only benevolence is a condition of human nature, an expression of human moral responsiveness. He thinks that natural benevolence, the will to do good, accounts in great part for the origin of morality. Hume suggests that benevolence, sympathy, fellow feeling, and concern for others are key ingredients in human nature. He concludes that our common humanity accounts for why moral responses are universal and comprehensive. Like Immanuel Kant, Hume contends that proper motive alone makes actions morally worthy (ibid: 20-32).

Hume also insists on the fact that it is the principle of sympathy that generates moral regard and concern for our fellow human beings. Sympathy, so Hume argues, consists of a double relation: the feeling for the pain of others and the motivation to relieve it (Kopelman & McCullough 1999: 315). If, as claimed by Titmuss, blood donation is the epitome of altruism, it should be understood as an example of what Hume calls sympathy (not passive compassion or contemptuous pity).

Turning back to MSM, the voluntary and unpaid donation of blood is undoubtedly a praiseworthy unselfish act. However, their life-style is linked to the possibility that their benevolence would put a blood-recipient at risk. Therefore, the blood banks have a moral duty to implement safeguards. The latter are not confined to MSM though. Even if the MSM motives are morally right it does not follow that they have a blanket “right” to donate. The only right they have, in this case, is not to be discriminated against unfairly. Altruism, in the case of MSM, is constrained by the blood banks’ duty.

It goes without saying that potential blood-recipients have the right to expect that the blood banks fulfil their duty of providing safe blood. Blood banks consider that a questionnaire, mandatory testing of donors, and testing of donated blood can only achieve this. It can be said that the motives are morally right. The question is whether the means to an end are morally justifiable. MSM claim that, since this policy results in excluding them from donation, it discriminates unfairly against them. Is it unjust and unfair to exclude MSM from blood donation? Now, fairness leads us to Rawls’ concept of “justice as fairness” (Rawls: 1971).

Rawls’ theory of justice rests on two principles. One, all members of society have the same scheme of basic rights and liberty; in other words, MSM have the same rights as, say, heterosexuals. However, their liberty,

like everybody else's liberty, is not unlimited. Two, social and economical inequalities are permissible provided that the inequalities do not interfere with fair equality of opportunity and benefit the least advantaged members of society. As blood donors, MSM claim that they are not given equal opportunity. The counterargument to the MSM's claim would be that all donors are subjected to the same rules (viz., completion of the questionnaire and HIV-testing of donated blood); hence, MSM are not specifically targeted. Would the least advantaged members of the community (in this case the blood recipients) benefit from the exclusion of MSM when they do not pass the safety test? The answer is clearly, no. It is because of a high level of HIV prevalence in general population as well as among Black young women of ages between 18 to 24 years in South Africa. The safety of blood cannot be ensured if all donors are not tested.

One can argue contra the in-/ex-clusion questionnaire that, if and only if all blood donation are individually tested by the NAT, the questionnaire becomes obsolete. In that case, the blood donation that tests positive would be discarded without the donor's knowledge. This would avoid discrimination (arguably at high financial cost for the BTS). However, this policy would be morally questionable since it would leave an HIV-positive potential donor ignorant of his/her serostatus, thus putting his/her sexual partner(s) at risk. And liberty, said JS Mill, ends where harm to other starts.

The screening questionnaire assumes that the potential donor gives true answers. However, this would not be enough to ensure safe blood as most donors do not know their HIV/AIDS status. Because the questions pertain to private matters such as sexuality, there is no guarantee that the questionnaire alone would ensure the safety of blood. Therefore, blood banks have the duty to practice additional security tests. These, again, apply to all donors. Failing to do so, because of the alleged discrimination that ensues, would lead to public mistrust and to endangering public health. Truthfulness is also expected from the BTSs. The potential blood recipients must be assured that all donations are tested by the NAT. Therefore, part of the conundrum, it hinges on the truthfulness of donors. Telling the truth is a Kantian obligation (Kant: 1785).

Concluding Remarks

In this research report, I have identified some of the complex, cultural, technical, and financial aspects of blood donation and blood transfusion in the South African particular, each one having ethical dimensions. Apartheid and its legacy as well as the cultural perceptions of Black potential donors do not promote the initiative of blood donation. At the same time, Black South Africans constitute the majority of people as well as the majority of people in need of blood transfusion. On the other hand, they also constitute the largest pool of people infected with HIV. Hence, the need for safe blood cannot be overemphasised.

The concept of discrimination has various interpretations: 1) unfavourable treatment based on prejudice (especially regarding race, age, or sex); 2) the power of observing differences; or 3) the ability of good judgement. Unfair discrimination – to treat or categorise people on the basis of prejudice - is morally and legally wrong. Does the exclusion of MSM from blood donation result in unfair discrimination? Homophobia is unfair discrimination for it condemns gay sexual practices as against nature and / or against God's will. Homosexuals claim the right to be whom and what they are, and that is fair enough. The question here, however, is that they claim the right to donate blood (apparently) together with the right not to complete the questionnaire (or to lie). The questionnaire includes

questions about one's private life (sexual). It seems that heterosexuals don't have serious objections to that (even if one may presume that they too may not tell all the truth and only the truth). However, if one (homo- or hetero-sexual) knows that blood donation results in harm to others (e.g. also a carrier of the hepatitis virus) truthfulness is morally required even if it results in being deferred as a blood donor. This is not discrimination but honesty, a renewed social responsibility towards the common good.

In this research report, I have tried to overview some of the complex issues faced by Blood Transfusions and Technology in the face of the HIV/AIDS pandemic. As identified, the Blood Transfusion Service is faced with a myriad of challenges in areas as diverse as e.g. technology, science, administrative, fiscal, cultural, and political. Many questions and decisions still remain, but it is my hope that Blood Transfusion Services will be able to find a balance between the ideal of recognising each person's dignity with and that of their duty to the public good. This may be realised, I suggest through dialogue and openness, honesty and reasoned deliberation on the part of every stakeholder for the good of all people.

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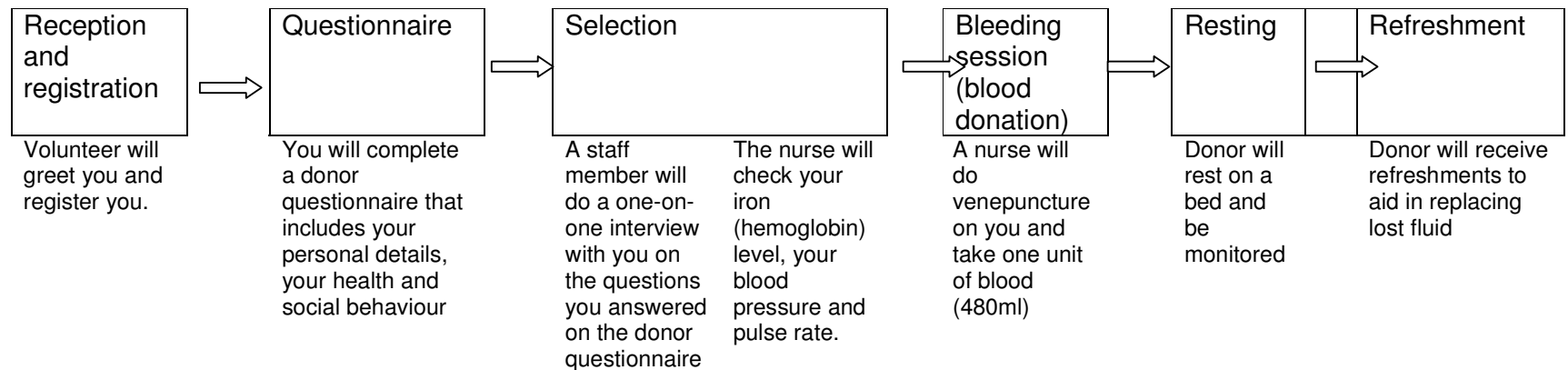
Addendum (1) Donor Form of the SANBS.

Self-exclusion questionnaire for risk behaviour and HIV/AIDS.

(Accessed 21 June 2006. Available at <http://www.sanbs.org.za/default.htm>.)

Addendum (2) The donation process^{xxxiii}

Donating blood is a safe and simple procedure that takes about 30 minutes. The actual donation process works like this:



^{xxxiii} A diagram of the blood donation process (source: <http://www.sanbs.org.za/donors/process.htm>)